

MI PRAMS Delivery

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Newborn Screening, MI PRAMS, 2004

Inside This Issue

	Page
Newborn Screening in Michigan	1
Newborn Screening tests results given to mothers	2
At a glance	2
Selected characteristics of infants screened	3
About Michigan's PRAMS	4

Points of Interest

According to respondents:

- ◆ In Michigan, 81% of mothers are aware that their newborns had Newborn Dried Blood Spot Screening done.
- ◆ Mothers who received prenatal information about birth defects screening were more likely to report that their newborn had Newborn Dried Blood Spot Screening (82%) compared to mothers who did not receive such information (73%).
- ◆ About 97% are aware that their newborns were screened for hearing loss.
- ◆ Almost all (99%) infants screened have health insurance.
- ◆ Approximately 90% of infants screened are seen within one week of hospital discharge.

The Michigan Department of Community Health offers both, Newborn Dried Blood Spot Screening and Follow up, and Early Hearing Detection and Intervention (EHDI) programs. Each program's staff works closely with hospitals and clinics statewide to ensure timely identification and appropriate follow-up. This issue of MI PRAMS delivery focuses on both Newborn Dried Blood Spot Screening and Early Hearing Screening.

Newborn Screening using dried blood spots is essential for the early detection of endocrine, hemoglobin, and metabolic disorders.

Phenylketonuria (PKU) was the first disorder screened for in Michigan (1965). PKU is a rare inherited disorder (1 per 16,500 newborns [1]), in which the body is unable to metabolize the amino acid phenylalanine.

Newborns develop PKU by inheriting an abnormal gene for metabolizing phenylalanine from each parent. Undiagnosed or mismanaged PKU can result in progressive brain damage. Management entails a diet restricted in certain foods (raw meats and eggs, soft cheeses etc.) with phenylalanine.

Regarding newborn hearing loss, on average, 33 babies are born with

hearing loss everyday in the US[2], making this disorder the most common birth defect [3].

Besides risk factors such as genetic predisposition and congenital infections, another risk factor includes, length of stay in the neonatal intensive care unit [4].

Early identification of hearing loss, when followed by immediate intervention, provides the potential of children developing communication and language skills equal with their hearing peers [5-7]. Healthy People 2010 Objective 28-11 aims to increase the percent of newborns screened for hearing loss by one month of age.

Newborn Screening in Michigan

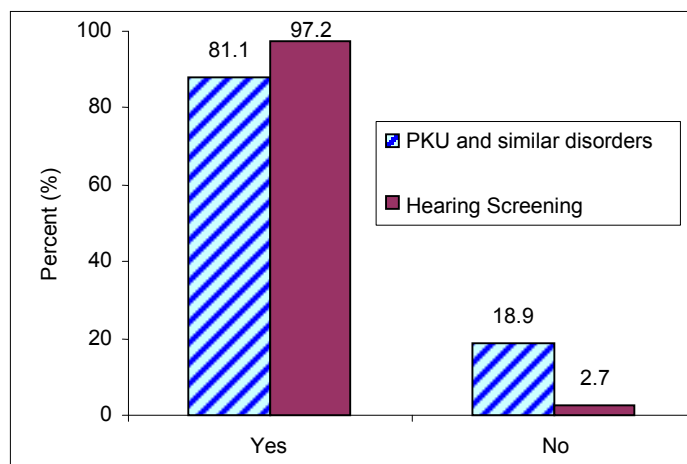


Figure 1: Prevalence of mothers aware of their infant receiving Newborn Screening.

2004 marks the beginning of Phase 5 of the PRAMS survey. Results are based on self-reported information and are therefore subject to response bias.

The percent of parents aware that their newborns were screened for conditions such as PKU was determined from responses to the question: *Before your baby was discharged from the hospital, did your baby have a screening test for conditions such as PKU, ..., and sickle cell disease?* Similarly, the percent of parents aware that their newborns were screened for hearing loss was derived from responses to the question: *Before your baby was discharged from the hospital, did your baby have a hearing-screening test?*

According to respondents, before leaving the hospital, a higher percent of mothers were aware that their newborns were screened for hearing loss (97%), than for PKU (81%; Figure 1).

Newborn Screening Tests Results Given to Mothers

References

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Mothers who indicated that their infants were screened for PKU or hearing loss, were asked if they were given their infants' screening results. A high proportion [88% (95% CI: 85.7 – 90.1)] reported receiving the hearing screening results while only 69% (95% CI: 64.9 – 73.5) reported receiving results for PKU and other metabolic disorders (Figure 2).

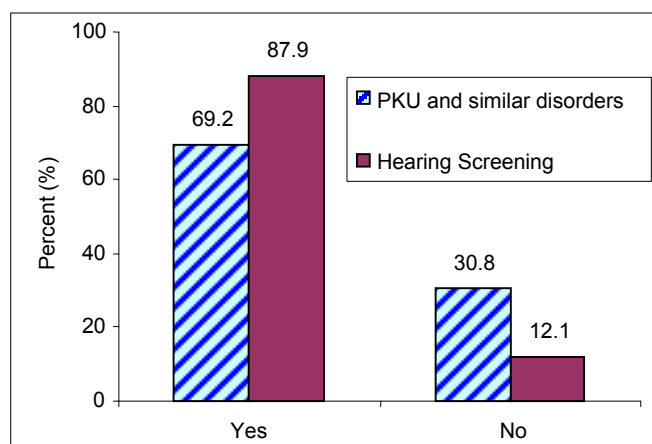


Figure 2: Prevalence of mothers, who reported receiving results from newborn hearing loss and PKU screening, 2004 MI PRAMS

At a glance

Metabolic Screening

- ♦ PKU (one of the more common metabolic disorders) occurs in an estimated 1 of out every 16,500 newborn in USA.
- ♦ Inherited copies of the mutated PKU gene from both parents is the main cause of the disorder.
- ♦ Late detection may lead to progressive mental retardation.
- ♦ If detected early enough, an affected infant can grow up with normal brain development by eating a diet low in phenylalanine.
- ♦ Some food items to avoid are meat, fish, nuts, dairy products and starchy foods such as potatoes, pasta, and corn.

Newborn Hearing

- ♦ Newborn hearing loss is the most common birth defect.
 - ♦ Some risk factors are genetic predisposition, congenital infections, mother's diabetes and drug and alcohol abuse.
 - ♦ Delayed detection may negatively affect emotional, communication, language and academic development.
- EHDI Program goals - "1-3-6"**
- ♦ All infants screened for hearing loss before **1 month of age**.
 - ♦ Those who do not pass their hearing screening shall have a diagnostic audiologic evaluation before **3 months of age**.
 - ♦ All infants identified with a hearing loss shall receive early intervention services before **6 months of age**.

The success of screening programs depends on follow-up services and connecting families to early intervention programs.

Selected Characteristics of Infants Screened

The proportion of infants who were screened and saw a health care worker within the first week of leaving the hospital (discharged) was determined. This was based on responses to the following PRAMS question: *Was your new baby seen by a doctor, nurse, or other health care worker during the first week after he or she left the hospital?*

Eighty eight percent (95% CI 85.2 – 91.1) of infants screened for PKU and other such disorders were reported as being seen within one week of hospital discharge (Figure 3).

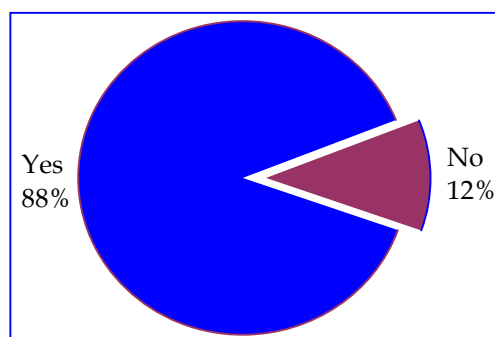


Figure 3: Proportion of infants seen within one week after leaving hospital among infants screened for PKU and other such disorders, 2004 MI PRAMS

Among infants screened for hearing loss, a similar percent, 89%, (95% CI 86.5 – 90.7) were reportedly seen by a health care worker within the same time frame (one week of hospital discharge).

The insurance status of the infants screened was examined. This information was ascertained by asking mothers: *'What type of insurance is your new baby covered by?'* Options for answers included *Medicaid, Private/HMO and MIChild*.

Figure 4 presents the distribution of insurance status among infants screened for PKU and

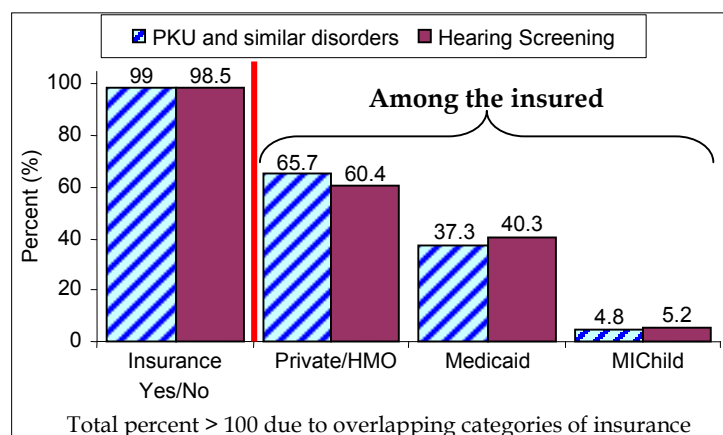


Figure 4: Type of insurance among infants screened, 2004 MI PRAMS

other such disorders along with hearing loss.

Almost all infants who were screened had health insurance. Private insurance/HMO covered 66% of those screened for PKU and other such disorders, while 37% was covered by Medicaid.

Of infants screened for hearing loss, 60% was covered by Private insurance/HMO and 40.3% by Medicaid per mothers reporting. The remaining percent (almost 5% for each, newborn dried blood spot and hearing screening) were covered by MIChild.

Recommendations

- ◆ Ensure all infants are screened for PKU and other such disorders along with hearing loss before hospital discharge.
- ◆ Educate expectant mothers about the importance of newborn screening
- ◆ Provide screening results to all mothers.
- ◆ Increase the proportion of infants seen within one week from discharge to assure better follow up.

Michigan's Newborn Screening Programs

Newborn Dried Blood Spot Screening

The State of Michigan introduced newborn screening for PKU and similar disorders in 1965. The state laboratory is the sole testing site in Michigan. Screening is done for a 48 metabolic, endocrine and hemoglobin disorders. In April 2005, a pilot project was initiated to include a panel of fatty acid oxidation and organic acid disorders. The state newborn screening program also has a comprehensive follow-up program for diagnosis, medical management, and quality assurance.

Early Hearing Detection and Intervention (EHDI) Program

The EHDI program contributes directly to infants having language and communication experiences that support development. As of March 2004, 100% of Michigan hospitals that deliver babies provide universal newborn hearing screening; the average age of diagnosis of hearing loss is less than four months of age. Approximately 200 infants per year are identified with hearing loss in Michigan.

For more information please contact your local health department. For information about Newborn Dried Blood Spot Screening call 517-335-8095. For information about EHDI visit www.michigan.gov/ehdi or call 517-335-8955.

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About Michigan's PRAMS

The Pregnancy Risk Assessment Monitoring System (PRAMS), a population-based survey, is a CDC initiative to reduce infant mortality and low birth weight. It is a combination mail/telephone survey designed to monitor selected self-reported maternal behaviors and

experiences of women who delivered a live infant in Michigan that occur before and during pregnancy, as well as early-postpartum periods. Information regarding the health of the infant is also collected for analysis. Annually, over 2,000 mothers are selected at random to participate from

a frame of eligible birth certificates. Women who delivered a low-birth weight infant were over-sampled in order to ensure adequate representation. The results are weighted to represent the entire cohort of women who delivered during that time frame.

*The MI PRAMS Delivery
staff takes this opportunity
to wish you a Happy and
prosperous New Year!*

**Suggested Citation**

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